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ABSTRACT

This final report describes Project WIN, a 3-year demonstration project in Massachusetts which served children diagnosed as HIV (human immunodeficiency virus) positive and their intravenous drug using parents. The transagency community based model was designed to serve the educational, medical, therapeutic and social needs of 25 preschool children a year and their families. Specific project goals included establishment and operationalization of a Transagency Board, implementation of casefinding efforts among community agencies, provision of home-based early intervention services, and dissemination of information to professionals and the public. Specifically the WIN model is comprised of six major program components: (1) referral, screening and intake; (2) transdisciplinary team assessment of child and family; (3) transagency board coordination; (4) individual family service plan completion; (5) home based intervention; and (6) case management. Individual chapters provide details about: (1) goals and objectives of the project; (2) theories or findings underlying the project's approach; (3) description of the training model; (4) description of the project's activities and accomplishments; (5) methodological or logistical issues; (6) evaluation findings and project impact; and (7) other sources of information. Appendixes include lists of the WIN Board members and presentations made, the Board opinion survey, a sample individualized family service plan, and a goal attainment scale. (49 references) (DB)

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PROJECT WIN: A DIRECT SERVICE PROGRAM FOR HANDICAPPED CHILDREN (BIRTH TO SIX) WHO ARE AT RISK FOR OR DIAGNOSED WITH HIV INFECTION AND THEIR IV DRUG USING PARENTS

FINAL REPORT

Handicapped Children's Early Education Program
U.S. Department of Education
Project Number:
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II. ABSTRACT

Project WIN: a direct service program for handicapped children (birth to six) who are at risk for or diagnosed with HIV infection and their IV drug using parents

A Handicapped Children's Early Education Project
Funded in Part by the Boston Foundation

Geneva Woodruff, Ph.D.
Director

Christopher R. Hanson, Ph.D.
Coordinator

WIN was designed as a community based model demonstration project to serve, during each year of funding, twenty five children under the age of six who were diagnosed as HIV positive and their IV drug using parents. The transagency service delivery model was used to help families meet their multiple educational, medical, therapeutic and social needs. These families have proven to be hard to reach, difficult to identify by traditional community programs, and difficult to engage in services. Therefore, they require creative and consistent outreach and intervention efforts by a transdisciplinary team capable of working with drug addicted families and their children.

The goals, components and activities of project WIN focused on:

1. The establishment and operationalization of a Transagency Board to ensure early, efficient casefinding, and comprehensive, family-focused services for handicapped and developmentally disabled children (birth to six) and their drug addicted parents.

2. The implementation of casefinding efforts among community agencies that came in contact with intravenous drug addicted parents in order to identify their children who were handicapped or developmentally disabled.

3. The provision of home-based early intervention services provided by a transdisciplinary team of professionals to increase the quantity and improve the quality of services to

handicapped and developmentally disabled children and their intravenous drug addicted parents.

4. The dissemination of information to professionals and the public about the needs of and successful practices for working with handicapped and developmentally disabled children and their intravenous drug addicted parents.

The WIN staff consisted of a director, a coordinator, three case managers, a clinical supervisor and consultants from the fields of family, occupational, physical and speech and language therapy. The case managers represented the fields of social work, nursing and child development. Staff members from these disciplines functioned together as a transdisciplinary team. They shared their skills and provided comprehensive services to the whole family. Case managers provided home-based services but had the flexibility to meet families at alternative sites (e.g., shelters, hospitals and foster homes). Each case manager carried a case load of eight to ten families. This kind of client-staff ratio enabled the case manager to provide the labor intensive attention these families required.

Child and family service needs were established over a series of intake interviews. To further assess child needs, the team then performed a developmental assessment in which the parents actively participated. Needs for intervention were incorporated into a service plan with the family and a primary service provider then presented the service plan draft to the transagency board. The transagency board was comprised of the health, education, addiction treatment and child and adult social service agencies in the community who typically worked with the clients WIN served. The board discussed the family case and provided input on the adequacy of the plan and made recommendations about additional goals and activities and how the plan could be coordinated in the service community. The service plan was then implemented by the parents and the primary service provider. Primary service providers were responsible for calling together case conferences for the family on a regular basis. These conferences were a gathering together of the other service providers who worked directly with family members. On the average, WIN clients were served by no less than seven agencies; these meetings, therefore these case conferences were necessary to close the gaps in service and to ensure that providers were not duplicating services. Service plans were reviewed by the transagency board periodically and were updated.

Casefinding efforts focused on providing information about the project to those programs and people in the community who were in either direct or indirect contact with IV drug users and their children. WIN staff provided information about the project through formal presentations at various agency and program sites in Boston. In addition, WIN brochures and posters that were distributed at key locations throughout the inner-city neighborhoods.

Information about handicapped children of drug addicted parents,

and of children and families at risk or positive for HIV infection, data about the behaviors and issues of these drug addicted and HIV infected families, and information concerning successful practices for working with them were disseminated in the greater Boston area as well as on a national basis. Dissemination activities included the publication of articles, presentations at national and local conferences and meetings, the development of a curriculum that can be used in training professionals, and the sponsorship of a statewide pediatric AIDS conference.

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IV. GOALS AND OBJECTIVES OF THE PROJECT

Goal 1: To establish and operationalize the WIN Transagency Board to insure early, efficient casefinding and comprehensive family-focused services for handicapped and developmentally disabled children (birth to six) and their intravenous drug addicted parents.

Obj. 1.1: To form the WIN Transagency Board.

Obj. 1.2: To operationalize the steering committee function of the Board.

Obj. 1.3: To operationalize the case management function of the Board.

Obj. 1.4: To operationalize the consultant function of the Board.

Goal 2: To conduct a casefinding effort among community agencies that come in contact with intravenous drug addicted parents in order to identify their infants and children (ages birth to six) who are handicapped or developmentally disabled.

Obj. 2.1: To assist the WIN Board in presenting WIN information to potential clients in order to enhance their ability to identify and refer special needs children (ages birth to six) of intravenous drug addicted clients who are eligible for services.

Obj. 2.2: To work with casefinding agencies to build trust with potential clients and increase client follow-through from referral to assessment.

Goal 3: To increase the quantity and improve the quality of service to handicapped and developmentally disabled children (ages birth to six) and their intravenous drug addicted parents.

Obj. 3.1: To provide a coordinated and family-focused casefinding, referral, assessment, direct service, transition, placement and follow-up system for WIN children and parents.

Obj. 3.2: To conduct intake interviews and arena developmental assessment services for all parents and children accepted into WIN.

Obj. 3.3: To write a family-focused service plan for all children and families accepted into WIN.

Obj. 3.4: To provide a home-based early intervention program to 25 handicapped or developmentally disabled children ages birth to six and their intravenous drug addicted parents who cannot be served in community early intervention or preschool programs, or who have illnesses, infections or communicable illnesses which prevent them from participating in group care.

Obj. 3.5: To provide early intervention services at alternative sites for handicapped and developmentally disabled children (ages birth through six) of intravenous drug addicted parents who are homeless, hospitalized, or whose parents are unable to come to the WIN offices or to have WIN staff come to their home.

Obj. 3.6: To refer children and parents who complete WIN services, as well as to provide transition and follow-up services for up to six months for those families referred to WIN but eligible for available community services.

Obj. 3.7: To provide inservice training and consultation to child and adult service providers who are serving WIN clients.

Obj. 3.8: To provide time-limited, psycho-educational support groups to parents enrolled in WIN services.

Goal 4: To disseminate information to professionals and the public about the needs of and successful practices for working with handicapped and developmentally disabled children ages birth to six and their intravenous drug addicted parents.

Obj. 4.1: To conduct workshops and present lectures at local, state, and national conferences and organizations on the WIN model and its relevance for the target population it serves.

Obj. 4.2: To submit articles to professional journals about the WIN model and its successful practices and findings.

Obj. 4.3: To disseminate written material and audio-visual materials developed by WIN.

Obj. 4.4: To disseminate information to professionals about the developmental and medical profiles of WIN children (ages birth to six) with AIDS, ARC, or HIV anti-bodies.

Obj. 4.5: To sponsor a national conference on the issues, needs and programs for handicapped and developmentally disabled infants and children ages birth to six and their intravenous drug addicted parents.

Obj. 4.6: To provide information to the public about the needs of and successful practices for handicapped and developmentally disabled children (ages birth to six) and their intravenous drug addicted parents.

Obj. 4.7: To provide consultation and technical assistance to other service providers in adopting the WIN model as well as to those developing programs for children with HIV infection and their families.

Obj. 4.8: To disseminate information to professionals about successful practices for working with families who have HIV infected parents and/or child.

Obj. 4.9: To develop, publish, and distribute a bi-monthly newsletter for professionals working in research, hospice, hospital-based and community-based services for children who are HIV infected and their families.

V. THEORIES OR FINDINGS UNDERLYING THE PROJECT'S APPROACH

This section discusses research findings that support the goals of the WIN model of service delivery. First, by establishing and operationalizing a transagency board, the WIN model seeks to ensure early, efficient casefinding and comprehensive family-focused services for children who are at risk or diagnosed as HIV infected. Second, by conducting casefinding efforts among community agencies that come in contact with intravenous drug addicted parents, the WIN model seeks to identify infants and children who are at risk or diagnosed as HIV infected. Third, by providing a coordinated system of direct service delivery based on transdisciplinary methods, the WIN model seeks to increase the quantity and improve the quality of services to these children and their families.

The goals of the WIN model are based on the following research supported principles:

1. Given the importance of the family to the child's development, services must be designed and implemented with consideration for the entire family's needs and resources. (Kaufman, 1985, 1986; Steinglass, 1985; Wermuth and Scheidt, 1986).

2. Early detection of children's at risk status or special needs and appropriate, intensive intervention provides them with a better chance for future success (Beller, 1979; Bricker, 1978; Bricker and Dow, 1980; Brooks-Gunn and Hearn, 1982; Clarke and Clarke, 1976; Friedlander, Sterrit and Kirk, 1975; Hanson and Schwartz, 1978; Sheehan, 1981; Swan, 1981).

3. A systems approach is needed to coordinate the services of multiple disciplines and agencies to efficiently serve children and families (Compher, 1984; Harshbarger and Maley, 1974; Arsenault and Prochaska, 1984).

4. Substance abusing parents can better meet the needs of their families when they are stabilized in their recovery from addiction, when their own needs are being met, and when they have the support and assistance of consistent workers from a manageable number of agencies. (Jeremy and Bernstein, 1984; Kaplan, 1987; Marcus, et al, 1984; Schultz and Gomberg, 1987).

5. Sufficient time is needed to build a relationship of trust with a substance using mother who is typically suspicious of

community services, usually difficult to engage in the therapeutic process, and often affected by low self-esteem, isolation, mistrust of professionals and institutions, and has long history of failure to succeed with service providers (Arnold, 1978; Colten, 1980).

6. Attention to the substance using mother's child care and parenting skills from a caring professional with whom she has developed a trusting relationship results in increased self-esteem, growth in parenting skills, increased stability in recovery, and increased satisfaction with the quality of family life (Savage-Abramovitz, et al, 1980).

7. Interagency collaboration is a means of increasing the benefits that families with special needs children can derive from the community service system. The benefits are felt by the child who enjoys streamlined services, the family who experiences less confusion and frustration, as well as the professionals who are able to more efficiently access needed services for their clients and feel more effective (Arsenault and Prochaska, 1984; Compher, 1984; Malinoski and Gressman, 1986; Sellin, et al, 1974, Stafford, et al, 1984).

8. The transdisciplinary team approach is an effective methodology that facilitates viewing the child and family as an interactive whole and provides professionals from different fields with a way to integrate their interventions and learn from each other (Fewell, 1983; Haynes, 1976; Woodruff and McGonigel, 1988).

9. A home-based intervention component is needed to fully engage families in the intervention process and for case managers to develop relationships with parents based on mutual trust and understanding (Carson, 1986; Frankel, 1988; Hegland, et al, 1987; Woodruff and Sterzin, 1988; Woods, 1988; Ziegelman, 1986).

VI. DESCRIPTION OF THE TRAINING MODEL

Project WIN was funded by the Handicapped Children's Early Education Program (HCEEP) and the Boston Foundation as a model demonstration program from October, 1986 through September, 1989. WIN was located in Boston. It annually served 25 or more children under the age of six and their intravenous drug using parents. All of the families served by WIN can be described as multiproblem in that they had physical, emotional and interactional needs. All of the children were at risk for or diagnosed as HIV infected, and all were at risk for developmental delay.

In December, 1988, notification was received from the Robert Wood Johnson Foundation of a four year grant of 1.8 million dollars to continue WIN services and to add center-based, prevention education, volunteer and extended family counseling services to its model. In January of 1989, this new four year project started under a new name, Project STAR. In addition, in October of 1989, the WIN model was funded by the Handicapped Children's Early Education Program as an outreach training project.

The WIN model demonstration program staff consisted of a director, coordinator, three case managers (with backgrounds in social work, education and counseling), a clinical supervisor, and consultants from the fields of family, occupational, physical, and speech therapy. Staff members from these different disciplines functioned as a transdisciplinary team, assessing children and planning family-focused interventions together.

All activities of the project were guided by a transagency board, composed of representatives from 28 different agencies who met monthly to plan and monitor services to families. Health, education, addiction treatment, and child and social service agencies were represented on the board. Board members referred children and families for WIN services, recommended services, arrived at a consensus regarding community service plans that were appropriate and manageable and reviewed and evaluated service plans at periodic intervals. They also provided direction and feedback for the project's dissemination activities. See Appendix A for a listing of the members of WIN's Transagency Board.

Direct and case management services to families were provided by the three case managers with consultation from occupational, physical, and speech therapy specialists and the board representatives. The case managers each worked with approximately

10 families. Small caseloads allowed the case managers to provide families with the intensive attention they often required. They provided direct services in families' homes as well as in alternate sites such as shelters, hospitals, foster homes, and motels, depending on where the family was residing. Case management was accomplished through collaborating with all involved service providers to design and work from one service plan that addressed all the family's service needs. Service providers talked with each other frequently and reviewed the service plan and interventions at regularly scheduled case conferences.

The WIN model is comprised of six major program components:

1. referral, screening and intake
2. transdisciplinary team assessment of child and family
3. transagency board coordination
4. individual family service plan completion
5. home-based intervention
6. case management

These components will be briefly described below.

Referral, Screening and Intake

Most families are referred by a board member, by a staff member from an agency represented on the board, by a community agency worker familiar with the project, or by the parent her/himself. Screening of eligibility and assessment of family needs take place during a series of intake meetings which occur at the family's residence, drug treatment agency, or other community agency. Through discussion, the team member conducting the intake (who usually will continue to work with the family) learns of the family's expectations and needs for services, what other agencies and workers are already involved with the family, the status of the parent's recovery from addiction, and often, the child and parent's HIV status and medical history. In addition, the parent is prepared for how she can work with the team during the transdisciplinary assessment of the child's developmental strengths and needs. The intake sets the stage for the parent's participation as a team member, and for the expectations that the team and parent will build a relationship of honesty and mutual trust.

Transdisciplinary Team Assessment of Child and Family

The transdisciplinary (TD) arena assessment is the format used to determine child strengths and needs and parent/child interactional needs. In the TD arena format, all members of the transdisciplinary team plan the assessment and the activities that will be used to determine strengths and needs of the child in all of the developmental domains. One member of the team, usually the team member who will be assigned to the family, facilitates the assessment along with the parent. Together, they engage the child

in a variety of play activities which will demonstrate his ability in each of the developmental areas. The other team members watch and record, then discuss their observations with the parent at the end of the assessment to determine whether the child's behaviors were typical. This is a time when the parent is asked to discuss with the team their concerns for the child, family issues, their evaluation of their strengths and needs in caregiving skills, and their priorities for services. The findings of the assessment, the parent's statements of concerns about the child's behavior or developmental skills, the parents' priorities for services, and the information gathered during the intake are then presented to the transagency board, which makes recommendations for services and interventions.

Transagency Board Coordination

At regular monthly meetings, the transagency board reviews information gleaned during the transdisciplinary assessment process and intake interviews, and recommends strategies for intervention and additional needed services. These board discussions are critical to the operation of the WIN transagency model; they streamline introduction of services, reduce red tape, and reduce duplication and fragmentation. They are the first opportunity for across-agency coordination of services, because the representatives of a variety of different agencies, with a host of different perspectives, discuss intervention strategies and recommend a service plan. Ideally, all service providers involved with the family operate from one service plan. Ongoing, regular case conferences and discussions among service providers ensure continued coordination of service delivery.

Individualized Family Service Plan (IFSP)

The family's expressed priorities for services and the team and board member recommendations for services to meet the child and family's needs are then drafted into an individualized family service plan. The primary service provider shares the draft with the family, and makes revisions as necessary. If the parent agrees with the service plan, the primary service provider and the other service providers then implement the plan. The IFSP is updated at least every four months at case conferences attended by the parent, primary service provider and other involved service providers.

Home-based Intervention

The WIN primary service provider, along with the parent, implements the activities of the service plan. Working directly with the family in their home, or alternative sites such as hospitals, shelters, foster homes, or residential motels, she/he addresses both child and family concerns. The role of the primary service provider is to act as counselor and educator regarding child development and parenting behaviors, to support the parent's

recovery, to advocate for and help the parent acquire necessary additional services, and to coordinate the efforts of other providers. When necessary, the primary service provider helps the family to obtain additional services, or ensure that the agencies which are supposed to be working with the family, are in fact fulfilling their obligations to the family.

Case Management

One service provider from the agencies providing services to the family is designated to be the primary case manager, and granted authority by the group to coordinate services. Usually, the WIN primary service provider assumes this role, however, in some cases a service provider from another agency who has built a trusting relationship with the family over a long period of time takes the role. Effective case management is the most critical element of the WIN transagency model. Coordination of the many agencies and providers is essential to the smooth delivery of services. Case management is accomplished through gathering these service providers together to plan and monitor services. Under the leadership of the case manager, these service providers define roles and responsibilities of each involved provider, organize, sequence and time service delivery, define lines of communication and agree on activities to meet the goals and objectives of the individualized family service plan. Ongoing case conferences with the service providers and parent are scheduled every 3-4 months to evaluate progress, identify new goals and objectives, and identify evolving service needs.

History and Evolution of the WIN Model

The WIN transagency model is rooted in the success of several model demonstration and outreach projects that have evolved over the past 13 years (Woodruff, 1975; 1975A; 1978; 1983; 1986; 1986A)

The first demonstration project, Step One, continues to be an ongoing early intervention program providing a combination of center and home-based services. It was established in 1974 to provide a program of community services to prevent or delay the institutionalization of handicapped infants and toddlers. This program currently serves approximately 100 infants and toddlers and their families in the South Shore area of Massachusetts. The children have established developmental delays or are at risk for delays because of environmental or biological factors.

Step One uses the transdisciplinary approach to deliver services to children and families (Haynes, 1976; Lyon, & Lyon 1980). This approach enables the developmental needs of the child and the support needs of the family to be addressed in a comprehensive and coordinated fashion. All team members, which include professionals from a variety of disciplines and the family, are directly involved in the design and evaluation of the child's program. To increase

the coordination of services, only one team member, the child's primary service provider, and the child's parent(s) or primary care provider implement and monitor the program together. The Step One programs have been quite effective. Responses from parents and staff consistently have indicated a high degree of satisfaction with the program and service delivery approach.

Because Step One was not able to serve the numbers of children in the South Shore area needing services, in 1975 staff applied to HCEEP for funding for a three year model demonstration program, called Project Optimus. Awarded funding, the Optimus team developed the transdisciplinary approach into a viable, time-efficient, cost-effective, and quality way to service a population of 40 children, birth to six years old, with moderate to severe handicaps and their families.

The transdisciplinary approach so effectively met the needs of the children, the parents and the team, that Project Optimus staff expanded the program into an outreach project to teach other early intervention and early childhood programs about the transdisciplinary approach and to assist them in the replication of the model.

From 1978 until 1985, Project Optimus/Outreach staff provided training to approximately 1500 professionals serving over 15,000 children and families. As a result of training 100 replication teams, project staff have refined the model (Woodruff, 1980; Woodruff & McGonigel, 1987) obtained information about how teams implement this approach, how team members' attitudes and practices evolve, and what administrative factors support or interfere with the effective implementation of the model. Numerous audiovisual and written materials were developed and training techniques and evaluation procedures refined (Woodruff & Sterzin, 1980; Woodruff, G. 1985).

The transdisciplinary model requires team members to plan for the child and the family in a comprehensive manner; the Optimus staff recognized that the principles of the model could be applied to coordinate the many services and agencies involved with the multihandicapped children and their families. Project Optimus/Outreach expanded the transdisciplinary model to increase interagency service collaboration and coined the term "transagency."

The transagency approach (Woodruff, 1987, Woodruff and Sterzin, 1988) reflects an expansion of the rationale and principles of the transdisciplinary model to community services. Just as the transdisciplinary model reduces service duplication, overlap, and fragmentation for the child and family within a single program, the transagency service delivery model reduces duplication of services for multiple agencies and bridges service gaps for the child, the family, and the service providers within the larger community. It

is applicable not only to early intervention and early childhood programs but to other programs as well.

The success of the transagency approach was demonstrated by Project PACT (Parents and Children Together) from 1983 to 1986. Project PACT provided family-focused, coordinated services to children, ages birth through six, with or at risk for developmental delays whose mothers were incarcerated or in treatment for alcohol or other substance abuse. Utilizing the transagency approach, representatives from 17 agencies (including day and residential alcohol and drug treatment centers, Framingham prison, family day care, day care, early intervention, preschool special education, Headstart, housing, rehabilitation, employment, job training, welfare) met monthly to ensure that the parents', the child's, and the family's needs were addressed in a coordinated and comprehensive fashion.

As a function of the success of Project PACT and the transagency model, the effective working relationships that had been established among Board agencies, and the continued needs of the children and their IV drug using families, the transdisciplinary and transagency models were again refined, expanded, and developed in Project WIN.

VII. DESCRIPTION OF THE PROJECT'S ACTIVITIES AND ACCOMPLISHMENTS

Goal 1: To establish and operationalize the WIN transagency board to ensure early, efficient casefinding and comprehensive family-focused services for handicapped and developmentally disabled children (ages birth to six) and their intravenous drug addicted families.

Twenty eight representatives (see appendix A) from state, city and private substance abuse treatment, health, education, social service and AIDS-related service programs in the greater Boston area joined the WIN transagency board and attended 36 monthly board meetings. In year one of the project, as a steering committee, the board members recommended and approved policies and procedures concerning referral and eligibility, intake procedures, implementing transagency case conferences and developing individualized family service plans (IFSP) for all families enrolled in WIN services. In years one through three, in their case management function, board members reviewed case presentations of 65 families enrolled in WIN, participated in discussion of child and family assessment information and recommended services and intervention approaches for each family. As consultants, the WIN board members provided input on the content and format of WIN awareness training sessions, reviewed the WIN brochure and a poster developed to attract referrals, and provided ongoing input on the activities of the project. In addition, board members served as the "talent" for a slide tape presentation developed by Project KAI on the transagency model of service delivery .

Goal 2: To conduct a casefinding effort among community agencies that come in contact with intravenous drug addicted parents in order to identify their infants and children who are handicapped or developmentally disabled.

Presentations, consultations and trainings to agencies in the Boston area were provided by WIN staff on the WIN service model. Presentation sites included hospitals, neighborhood health clinics, grass roots community programs, drug treatment facilities and social service agencies. Consultation and training activities were planned to provide information to child agencies and substance

abuse treatment staff on the characteristics and needs of children in drug abusing families and to social service agencies and grass roots community programs on the needs of families with AIDS. Special emphases at all presentations were given to the WIN referral process and eligibility criteria so that appropriate families could be referred for services. In addition, a poster designed to provide information to parents so that they could make self-referrals was displayed in a variety of drug treatment facilities and health clinics.

In total, 81 presentations, trainings and consultations were made to agencies and programs in the greater Boston area. As a result of these casefinding activities, 65 families were referred and accepted for WIN services.

Goal 3: To increase the quantity and improve the quality of services to handicapped and developmentally disabled children (ages birth to six) and their intravenous drug addicted parents.

Activities in year one revolved around the establishment of all procedures related to intake, assessment, service delivery, documentation of IFSP's for each family, documentation of all case related direct and indirect services for children and families, and the building of cooperative relationships with associated service delivery agencies and personnel in the Boston area. By the end of year one, the WIN staff were serving a caseload of over 25 families. Throughout years two and three, the provision of home-based early intervention services, transagency case management and the documentation of case related activities remained primary activities of the WIN direct service team.

In total, 65 families were referred for WIN services, were assigned a primary service provider and case manager, completed the intake process which included a child and family transdisciplinary developmental assessment, were presented to the transagency board for service recommendations, participated in the development of an IFSP and engaged in home-based services. Referrals for additional family support services such as housing, medical care, food, visiting nurse services, clothing, transportation, day care, respite care, etc. were made as needed and case conferences with cooperating agencies were held on an average of every four months. All activities related to cases were documented in detailed case notes. IFSP's and goal attainment scales were used to document family priorities and needs and to monitor progress. WIN services were provided in the home and at hospitals, drug treatment facilities, motels, shelters for the homeless, foster homes, and residential facilities for children. Efforts were made to meet families where they felt most comfortable in order to reach them and to build a caring and trustworthy relationship.

Goal 4: To disseminate information to professionals and the public about the needs of and successful practices for working with handicapped and developmentally disabled children (ages birth to six) and their intravenous drug addicted parents.

During the first year of the project, dissemination activities centered on planning and developing materials for dissemination including a brochure, annotated bibliography, training modules for presentations, and submitting articles for publication. In years two and three of the project, dissemination activity focused on presentations to local, state and national audiences at meetings, conferences and workshops. Presentations included information about the project and the service needs of the children and families served by WIN. Additional dissemination activities in years two and three included the development of a training curriculum to be used with other professionals and agencies who may be interested in starting programs similar to the WIN Transagency model of service delivery, and the sponsorship of a state-wide conference on pediatric AIDS.

In total, during the course of the three year demonstration period, over 2500 professionals participated in workshops, lectures, or conference presentations about WIN and the Transagency model of service delivery. Appendix B provides a listing of 30 presentations the project director made during the project's three year period. In addition, the following publications about the project were developed by the project's staff and reached a national audience:

Woodruff, Geneva; Sterzin, Elaine; Hanson, Christopher. "Serving Drug Involved Families With HIV Infections in the Community: A Case Report", Zero to Three, Volume IX, No. 5, June, 1989.

Woodruff, Geneva; Sterzin, Elaine. "Project WIN: The Foundation for Children With AIDS", Caring Magazine, August, 1988.

Garland, Corrine; Woodruff, Geneva; Buck, Deana. "Case Management", White Paper for the Division of Early Childhood. June, 1988.

Woodruff, Geneva; Sterzin, Elaine. "The Transagency Approach: A Model for Serving Children with HIV Infection and Their Families", Children Today, May-June, 1988, pp. 9-14.

Woodruff, Geneva; McGonigel, Mary. "Early Intervention Approaches: The Trandisciplinary Model", Early Childhood Special Education - Birth to Three, Council for Exceptional Children, Reston, VA, July 1988.

Woodruff, Geneva. "Working With Infants, Toddlers and Their Families: What We Do and How We Keep Going", Zero to Three, Bulletin of the National Center for Clinical Infant Programs, Volume VII, No. 5, June, 1987.

The curriculum that can be used in training workshops for professionals who are looking to start programs similar to the WIN model includes the following topics: the psychological impact of HIV on the child and the family; strategies to use in dealing with drug addicted parents; and, helping families to access community services. The curriculum was used as an integral component of the training and technical assistance that was provided by WIN staff to the staff of project STAR. Project STAR is funded by the Robert Wood Johnson Foundation and continued the work of project WIN after September 30, 1989.

The project director served on the planning committee of the Fifth Annual National Pediatric Aids Conference, September 6, 7, and 8, 1989 in Los Angeles, California, which was supported by the Office of Maternal and Child Health, Bureau of Maternal and Child Health and Resource Development, Department of Health and Human Services. The director was also invited to attend a September 8th and 9th, follow-up workshop to this conference. The project director used the results of the Los Angeles conference to help with the planning of a two-part Massachusetts state wide conference on Pediatric AIDS that was held in September in Worcester and in November in Boston. This state wide conference was sponsored by the State Department of Public Health and supported by project WIN.

During the three year period of the project, staff also responded to over 160 formal requests for information. These requests ranged from inquires about program services and where additional services could be found in the community, to information about the needs of families whose children were HIV infected, to questions concerning program design and resource allocation. Project WIN staff responded to these requests for information by conducting phone conversations with the interested parties, by visiting with other agencies and programs and making awareness presentations, by sending information through the mail and by making referrals to other programs or professionals.

The director of the project continually disseminated information about the project and the service needs of children who are at risk for or diagnosed as HIV infected through her professional affiliations, board memberships and through her work as the executive director of the Foundation for Children with AIDS (see listing of these affiliations below). The Foundation for Children

with AIDS was formed to bring together families and professional working with children with AIDS. The purposes of the foundation include to organize a national forum for children with AIDS and their families, to promote quality and comprehensive services and to disseminate information about the issues and needs of children with AIDS and their families. On a bi-monthly basis, the foundation publishes a newsletter called the "Children with AIDS Newsletter (CAN)". Included in the many issues of the newsletter that have been published have been articles about WIN and the transagency model of service delivery.

Affiliations for the Project Director, Geneva Woodruff, Ph.D.

A. Fellowships and Professional Offices

-Executive Director, Foundation for Children With AIDS, 1988- present.

B. Professional Affiliations

-Member of the Surgeon General's Planning Committee for the 5th National Conference on Pediatric AIDS, Los Angeles, September 1989.

C. Board Memberships

-Visiting Nurses Association, Inc., 1987 - 1988
-Board of Directors of Museum Council, Museum of Fine Arts, Boston, MA, 1983 - 1989
-Massachusetts Early Childhood Education Task Force, 1984 - 1985
-Associate Board Member, Massachusetts Developmental Disabilities Council, 1983 - present
-Family Systems Project, University of Kansas, 1983 - present
-Early Childhood Committee, Massachusetts Developmental Disabilities Council, 1981 - present
-INTERACT -- a national organization for early intervention professionals, 1978 - present
-International Adoptions, 1988 - present

VIII. METHOLOGICAL OR LOGISTICAL ISSUES

Readers of this report are referred to three key publications by members of the WIN staff that in part discuss methodological and logistical issues concerning the project and the provision of services to children who are HIV infected and their families:

Woodruff, Geneva; Sterzin, Elaine; Hanson, Christopher. "Serving Drug Involved Families With HIV Infections in the Community: A Case Report", Zero to Three, Volume IX, No. 5, June, 1989.

Woodruff, Geneva; Sterzin, Elaine. "Project WIN: A Program for Children With AIDS", Caring Magazine, August, 1988.

Woodruff, Geneva; Sterzin, Elaine. "The Transagency Approach: A Model for Serving Children with HIV Infection and Their Families", Children Today, May-June, 1988, pp. 9-14.

IX. EVALUATION FINDINGS AND PROGRAM IMPACT

The effectiveness of the WIN model has been substantiated in a variety of ways during the project's demonstration period. As part of its evaluation plan during the demonstration period, the project collected data on:

a. children and families,
b. its staff
c. the WIN transagency board
d. the amount, types and effects of WIN awareness training and dissemination activities.

In addition to the above sources of program effectiveness, an ethnographic evaluation team from Northeastern University, headed by Dr. Lee Ann Hoff, was hired to perform an independent third party assessment of the effects of the project. The goals of this assessment were to identify how the WIN model affects the lives of the programs' families from the perspective of a sample of families who have been observed and interviewed over a period of time, to identify those factors in family-staff interaction which may have a positive and/or negative impact on the families' perception of services, and to identify those aspects of interstaff and transagency board relationships that may be related to the program's impact on families. The data collection methods of the ethnographic team include performing in-depth interviews with family members, staff and WIN board members, observing families in their daily routines, documenting observations of parent/child interactions, recording parent's perceptions of the services they receive, and observing the WIN staff during meetings, assessments and home visits.

Data from the above sources indicate that the WIN model is an effective approach for serving children who are at risk for or diagnosed as HIV infected and their families, and that the WIN model can be disseminated through providing staff with training and technical assistance.

The data of the WIN evaluation period support nine effectiveness statements:

1. The WIN model of service delivery provided children at risk for or diagnosed as HIV infected and their families with an effective case management system for their unique and special needs.

The families interviewed by the ethnographic team have offered unconditional praise and satisfaction for the service provided by the WIN case managers. Evaluative comments are striking in their contrast to the families' experiences with service providers from some other agencies. Particularly significant is the families' appreciation of the caseworker coming to the home, the regularity of these visits, and the coordinating and linkage tasks necessary for accessing the various services needed when addiction and the threat of AIDS affects a family. The very fact of staff's willingness to come to their homes and "be" with them provides the families experiential validation of being valued in contrast to the shunning they often experience from other segments of society.

2. The WIN transagency board facilitated coordination of service delivery and a sense of community and common purpose among board members.

WIN Transagency Board members indicate that their participation on the board has increased their understanding of the different community services available for children at risk for or diagnosed as HIV infected and their families. They believe that the deliberations of the WIN Board and case discussions result in: increased coordination of services among board agencies; improved case management services for the families involved; and significant reduction in duplication of efforts. Board members believe that these case management discussions represent a cost-effective method to obtain intervention ideas and points of view from many different perspectives and that through their experiences on the board their view of children and families has broadened. Finally, board members believe that through their participation on the WIN Board they became more involved in the local service community, that mutual support among agencies increased, and that a strong advocacy base for services for children at risk for or diagnosed as HIV infected and their families was established. A summary of findings from an opinion survey administered to WIN Board members in February, 1989 and a copy of the survey can be found in Appendix C.

3. WIN staff members increased their abilities to work with families to identify family-focused goals and objectives through use of transdisciplinary methods of team and family involvement.

In each of it's three years of demonstration, the WIN project has served an average of twenty-five families. Individual family service plans (IFSPs) were written with each family and reviewed and updated at six month intervals. Each IFSP contained an average of 4 family-focused outcome statements and each outcome statement was accompanied by an average of 5 strategies for successful completion. Outcome statements and strategies that have been successfully completed by parents in collaboration with work by WIN staff members have included: remaining drug free; accomplishing steps to maintain adequate housing; finding an adequate job; finding and using day care that met the family's needs and resources; obtaining and attending family counseling sessions;

obtaining food stamps; obtaining transportation; developing a support system to remain drug free; obtaining and attending drug rehabilitation counseling; identifying and obtaining age appropriate toys for their children; experimenting with a variety of nutritionally sound foods for their children; continuing with the child's medical follow-up at a local hospital; setting limits for the child and learning ways to give appropriate discipline; enhancing the child's play skills, initiative and attention; and enhancing the child's development in gross motor, fine motor, cognitive, language and communication, social and self-help areas. A sample IFSP can be found in Appendix D.

4. The developmental attainment levels of children at risk or diagnosed as HIV infected were successfully monitored through WIN's use of transdisciplinary arena assessment methods.

The WIN transdisciplinary team conducted arena developmental assessments with families enrolled in the project at intervals of 6 months. As part of the arena assessment process, the WIN team administered the Hawaii Early Learning Profile (HELP) developmental assessment (Furuno, et al., 1979) at each assessment. Results from the HELP were discussed with each parent in terms of whether the child's assessed range of functioning fell within normal limits across skill domains. Developmental assessment results from a sample of WIN cases can be found in Appendix E. Results from the HELP were also used by the WIN team as a stimulus to start the IFSP development process with parents or as a start for reviewing IFSP progress at 6 month intervals.

5. Child-focused goals were achieved through a combination of home- and center-based services provided by WIN primary service providers.

6. Parents and other family members achieved their IFSP goals by learning how to access and use community services and became better advocates for their families through weekly contact with WIN primary service providers.

During the 3 year demonstration period, the WIN team used the Goal Attainment Scaling (GAS) procedures (Kiresuk and Lund, 1976; Simeonsson, Huntington and Short, 1982) to help measure the attainment of both child and parent-focused IFSP outcome statements and strategies. The project used perhaps the most straight forward method to report GAS results (Bailey, et al., 1986) by plotting initial and attained levels of performance on each IFSP outcome statement using a chart with an ordinate on which values ranged from -2 to +2. A sample GAS and corresponding chart can be found in Appendix F.

GAS results from a sample of 10 WIN cases covering the period February, 1987 to June, 1988 are as follows:

* 3% of those outcome statements (Goals) developed by parents and the WIN team resulted, after intervention, in the worst expected outcomes (i.e. received attainment levels of -2 on the GAS);

* 16% of the outcome statements developed by the parents and the WIN team resulted, after intervention, in less than expected outcomes (i.e., received attainment levels of -1 on the GAS);

* 29% of the outcome statements developed by the parents and the WIN team resulted, after intervention, in the expected outcomes projected (i.e., received attainment levels if 0 on the GAS);

* 19% of the outcome statements resulted, after intervention, in more than the expected outcomes (i.e., received attainment levels of +1 on the GAS);

* 33% of the outcome statements developed resulted, after intervention, in the best expected outcomes projected by the family and the WIN team (i.e., received attainment levels of +2 on the GAS).

7. Community service agencies in the Boston area increased their ability to identify and refer children who were at risk or diagnosed as HIV infected as a result of awareness training sessions and materials provided by WIN staff members.

As a result of the awareness presentations that WIN staff made to more than 81 Boston area community service agencies, WIN received 65 referrals of children in need of services who went on to be enrolled in the project.

8. Professionals and the lay public increased their knowledge about the needs of and successful practices for working with children who were at risk for or diagnosed as HIV infected and their intravenous drug addicted parents.

Over 2500 professionals participated in workshops, lectures, or conference presentations about WIN and the transagency model. (See Appendix B for a listing of 30 presentations made by the director of the project.) In addition, a listing of publications by project staff can be found on pages 19 and 20 of this report . Project staff also responded to over 160 formal requests for information about the project and the service needs of children who are HIV infected and their families.

9. The WIN model provided the necessary structure to develop a computer assisted data base to describe the common bio-demographic characteristics of families whose children were at risk for or diagnosed as HIV infected, as well as to detail the weekly types of contact necessary by staff members to successfully provide services.

The data base organized information across 9 major areas of information and provided descriptive statistics concerning:

a. the child's biological family;

b. significant others involved with or responsible for the child;
c. agencies involved with the family;
d. family history;
e. substance use history;
f. housing information;
g. social support network information;
h. developmental assessment information;
i. daily contact information including home visits, visits with the family outside the home, telephone time with the family, writing time regarding the family, collateral visits with community agencies regarding family issues, arena assessment visits, case conferences and supervision sessions regarding case related issues.

X. WHERE FURTHER INFORMATION CAN BE FOUND

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XI. APPENDICES

APPENDIX A

WIN BOARD, UPDATED FEBRUARY 1989

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APPENDIX B

PRESENTATIONS MADE BY PROJECT DIRECTOR, GENEVA WOODRUFF, PH.D.

"Serving and Caring for Children With AIDS and Their Families," Council for Exceptional Children Conference, Nashville, TN, November,1988.

"Case Management for Special Needs Children and Their Families," Idaho Children's Conference, Sun Valley, ID, October, 1988.

"Early Intervention Services Under PL 99-457," Pennsylvania Department of Public Health and Education, State Conference, Harrisburg, PA, October, 1988.

"Using a Transagency Model to Serve Children With HIV Infection and Their Families," Northwest Regional States Conference, Eugene, OR, October, 1988.

"Serving Children With AIDS and Their Families", International Family Conference, Stockholm, Sweden, August, 1988.

"The Impact of AIDS on Early Childhood Special Education", Infants/Families/Professionals:Perspectives and Strategies for Intervention, St. Cloud, MN, August, 1988.

"Serving Kids With AIDS", Gay and Lesbian Health Conference, Boston, MA, July 21, 1988.

"The Transdisciplinary and Transagency Models of Service Delivery", Case Collaborative School District, Wheaton, IL, June, 1988.

"Barriers To Care For Infants", Massachusetts Perinatal Association, Sturbridge, MA, April, 1988.

"Case Management", Idaho State Department of Public Health, Boise, ID, April, 1988.

"Serving HIV Infected Children", Pediatric AIDS Conference, East Rutherford, NJ , April, 1988.

"Transagency Case Management for At Risk Infants", 1988 Health Conference, Boise, ID, April, 1988.

"Case Management and The Transdisciplinary Approach to Service Delivery", Delaware Department of Education, Dover, DE, March, 1988.

"The Transdisciplinary Model of Service Delivery", Colorado Department of Education, Denver, CO, March, 1988.

"The Transdisciplinary Model of Service Delivery", St. Simons Island, GA, January, 1988.

"Project WIN: A Transagency Model of Community Based Services for At Risk Children and Families", National Center for Clinical Infant Programs, Washington, DC, Dec, 1987.

"Family Roles In Case Management", DEC Conference, Denver, CO, November 1987.

"The Transagency Model: A Service Delivery Approach for Children with HIV Infection and Their Families", UCLA, Los Angeles, CA, November, 1987.

"Transdisciplinary Workshop", DEC Conference, Denver, CO,

November, 1987.

"Transdisciplinary Workshop", DEC Conference, Denver, CO, November 1987.

"Serving Children At Risk for AIDS and Their Families", Family Therapy Conference, Chicago, IL, October 1987.

"Project WIN: A Transagency Approach for HIV Infected Children and Families", American Psychological Association, NY, August, 1987.

"The Transagency Service Approach: For Young Children of Alcoholic and Addicted Mothers", CEC, Chicago, IL, April, 1987.

"The Transagency and the Transdisciplinary Service Models: Two Case Management Approaches", Child Development Resources Institute, Williamsburg, VA, July, 1987.

"The Transdisciplinary Model of Service Delivery and Issues in Working with At-Risk and Handicapped Children and Their Families", Essential Early Education Birth to Three Spring Conference, Burlington, VT, 1986.

"An Introduction to the Transdisciplinary Model of Service Delivery",Freehold, NJ, 1986.

"Issues, Solutions and Recommendations for Infants and Young Special Needs Children and Their Families", Third Annual INTERACT Conference, Salve Regina College, Newport, RI, 1986.

Panelist on Advocate Court Presentation, Child Welfare League of America, Washington, D.C., 1986.

"What Do We Mean by Comprehensive Services in Early Intervention", Keynote, DEC/CEC. Louisville, KY, 1986.

APPENDIX C

THE WIN TRANSAGENCY BOARD OPINION SURVEY

date completed _____

1. How long have you been a Board member? (please circle)

   a. less than 1 year
   b. 1-2 years
   c. more than 2 years

2. How often do you attend Board meetings?

   a. regularly (i.e., average of one absence in four)
   b. sometimes (i.e., average of two absences in four)
   c. rarely (i.e., average of three absences in four)
   d. have not attended

INSTRUCTIONS: For items 3-18, please respond to each statement by circling the number that best represents your opinion about the WIN Board and services to children at risk for, or diagnosed with HIV infection and their families.

	strongly disagree		not sure		strongly agree
3. I believe that my participation with the WIN Transagency Board has increased my understanding of the different community services available for families and children.	1	2	3	4	5
4. I believe that my participation with the WIN Board has increased my understanding of the roles and responsibilities of other agencies in the community.	1	2	3	4	5
5. I believe that my participation with the WIN Board has broadened my awareness of the problems and needs of children and families.	1	2	3	4	5
6. I believe that my participation with the WIN Board has increased my awareness of intervention strategies to help meet the needs of children and families.	1	2	3	4	5
7. I believe that the deliberations of the WIN Board result in increased coordination of services among Board agencies.	1	2	3	4	5

8. I believe that the deliberations of the WIN Board can result in increased coordination of services among those agencies in the community that have contact with Board members but are not represented on the Board.	1	2	3	4	5
9. I believe that the deliberations of the WIN Board improve casefinding among the Board agencies.	1	2	3	4	5
10. I believe that my contributions to Board discussions result in improved case management for families.	1	2	3	4	5
11. I believe that the contributions of my fellow Board members to the case management issues discussed by the Board result in improved case management.	1	2	3	4	5
12. I believe that the deliberations of the WIN Board reduce administrative red tape among agencies, thereby increasing available services.	1	2	3	4	5
13. I believe that the deliberations of the WIN Board reduce the duplication of services to families.	1	2	3	4	5
14. I believe that the time I spend each month working with the WIN Board is well spent.	1	2	3	4	5
15. I believe that Board deliberations result in increased consistency in the delivery of services among member agencies.	1	2	3	4	5
16. I believe that the Board case management discussions represent a cost-effective method to obtain intervention ideas and points of view from many different perspectives.	1	2	3	4	5
17. As a result of my experience on the WIN Board, I believe that my view of children and families has broadened.	1	2	3	4	5
18. As a result of my participation on the WIN Board, I feel more involved in the service community.	1	2	3	4	5
19. I believe that through frequent contact at WIN Board meetings, members gain support from one another.	1	2	3	4	5

20. I believe that communication among the WIN Board members is increased as a result of their participation at Board meetings.	1	2	3	4	5
21. I believe that through participation at WIN Board meetings, members and the agencies they represent form an advocacy base for services and their clients.	1	2	3	4	5

22. Please rate your participation on the WIN Board in terms of its value.

very little or no value	less than adequate	adequate	time well spent	very valuable
1	2	3	4	5

23. Please list and rank in order the three most important contributions you believe the WIN Board makes:

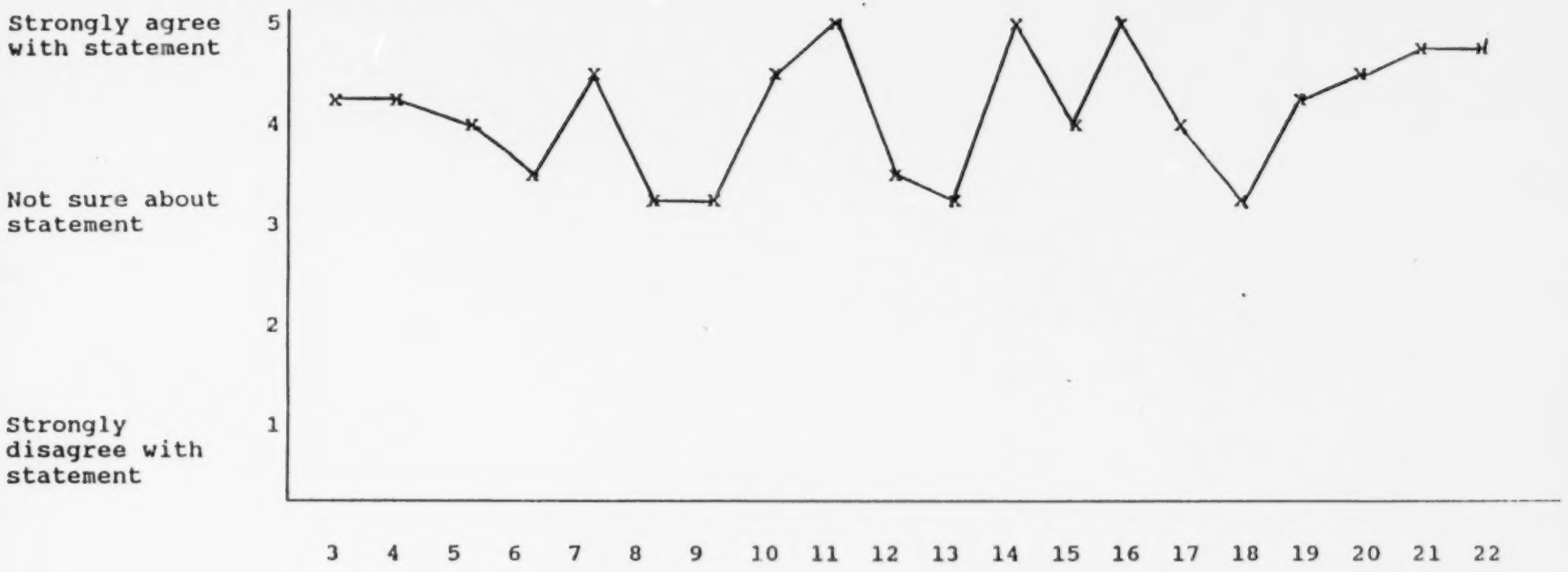
a. _____
b. _____
c. _____

24. Please list and rank in order the three most important things you believe the WIN Board can do to improve its functioning:

a. _____
b. _____
c. _____

25. Comments (Please indicate any general comments you wish to make.)

WIN COMPOSITE FINDINGS FROM 2/89 WIN BOARD OPINION SURVEY


Strongly agree with statement
5
4
Not sure about statement
3
2
Strongly disagree with statement
1
3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22

**Statement Numbers

(* 29 Different Agency Representatives sit on the WIN board)

(** See actual board survey for corresponding statements for which these numbers refer to)

APPENDIX D

Sample Individualized Family Service Plan #2

The Crowder Family

(See vignette #2, Chapter Three, pages 20-21)

The IFSP for the Crowder family was developed by Geneva Woodruff and Chris Hanson at Project WIN in Brighton, Massachusetts, with assistance from Ibby Jeppson of ACCH and Patti Place of NASDSE. The format for this IFSP was developed by Roxane Kaufmann of NEC*TAS and Mary McGonigel and Josie Thomas of ACCH to provide a simple format that includes all the Public Law 99-457 requirements, yet is still "family friendly." This IFSP would have been handwritten to emphasize the informality and flexibility that should characterize IFSPs, but it was necessary to type it for reproduction clarity.

A family with a child who is HIV positive was included in this document to illustrate that some children and families will require services that go beyond those traditionally associated with early intervention and to highlight the collaboration and coordination among agencies that is critical if Public Law 99-457 is to fulfill its promise to these children and families. The transagency model developed at Project WIN is an approach that has proven effective in meeting the multiple needs of families whose children are HIV positive in a way that is respectful of family values and that builds on the strengths and resources already present in families.

Reference

The following sample IFSP has been reproduced from the following source:

The Development of Guidelines and Recommended Practices for the Individualized Family Service Plan: An Overview. The Office of Special Education Programs, the National Early Childhood Technical Assistance System (NEC*TAS), University of North Carolina at Chapel Hill. 1989.

Individualized Family Service Plan (IFSP)

Child's Name: Mary Crowder

Birthdate: 10/10/86 **Age:** 23 months

Developmental Levels:

15-18	months	Fine Motor	12-15	months	Gross Motor
15-18	months	Cognitive	18-21	months	Language
12-15	months	Self-Help	18-21	months	Social/Emotional

Child Strengths and Needs:

Mary's developmental strengths are in her ability to communicate and interact with her mother, aunt, and brother and sister. Despite her many health problems, Mary's temperament is sunny, and her disposition makes it easy for her to get the adults around her involved with her.

Mary's physical health varies considerably as a result of her ARC, and this affects her motor development, which is very uneven. Mary has persistent diarrhea and recurring ear infections. Mary is a fussy eater and sometimes throws food she doesn't like or want. She doesn't have many opportunities to play with or be around other young children, which would allow her to make the most of her good language and social skills.

Child's Name: Mary Crowder

Family Strengths and Needs:

Theresa is deeply committed to keeping her family together and to caring for Mary at home as long as she can. Theresa's periods of being sick with ARC make it hard for her, at times, to manage the demands of taking care of Mary. She has a lot of help from Yvonne and Julie, both of whom are great sources of support and can be relied on to help out whenever they are needed. Yvonne goes grocery shopping for the family, helps Julie with her school work, takes Mary and Theresa to medical appointments, and has made a home for Roger with her family. Because Theresa relies so heavily on Yvonne and because Yvonne disapproves of Theresa's drug use so strongly, Theresa wants to enter a treatment program again.

Julie is devoted to her little sister and helps out with her every chance she gets. Julie says she wants to be a very important part of Mary's IFSP team.

Right now, mealtimes are not good times at the Crowder's. Theresa is often too tired to cook dinner and then coax Mary to eat, but she worries about Mary not getting enough to eat and wants to see her grow stronger. Julie manages dinner whenever Theresa is too tired, but she isn't sure what she can make for dinner that Mary would like and want to eat. Theresa also wants some time alone during the day to rest when she isn't feeling strong, and she hopes Mary will have a chance to be around other young children. Theresa needs a stroller in order for her to be able to take Mary out of the house.

Outcomes:

1. Theresa wants to control her drug addiction in order to maintain her good relationship with her sister.

2. Theresa wants Mary to be in day care, so that Theresa has some time to rest during the day and so that Mary can have a chance to play with children her own age.

3. Theresa and Julie want some help at mealtimes in order for Mary to learn how to eat more foods, be less fussy, and grow stronger.

4. Mary will have physical therapy in order to increase her body strength and mobility and make it possible for Theresa and Julie to take care of her at home.

Child's Name: Mary Crowder

Outcome: # 1

Theresa wants to control her drug addiction in order to maintain her good relationship with her sister.

Strategies/Activities:

1. Theresa, Lizzie (the WIN service coordinator), and Lucy (Theresa's hospital social worker) will discuss Theresa's options for a drug treatment program.

2. Theresa will choose the option she prefers and will call to refer herself within a week of the discussion.

3. If there is a waiting list, Lucy will arrange for Theresa to be have a priority admission because of her illness.

4. Theresa will complete the intake process for the treatment option she chooses and will go to treatment sessions as scheduled. Lizzie or Lucy will go with Theresa to her appointments whenever she asks.

5. Lucy, Lizzie, and Yvonne will help and support Theresa, encouraging her efforts. Theresa will tell Lizzie and Lucy when she feels like using drugs, and they will tell Theresa whenever they think she is using drugs.

Criteria/Timelines:

Theresa will determine if she is making progress overcoming her drug addiction. She suggested that she review her progress with Lizzie every month.

Child's Name: Mary Crowder

Outcome: # 2

Theresa wants Mary to be in day care so that Theresa has some time to rest during the day and so that Mary can have a chance to play with children her own age.

Strategies/Activities:

1. Lizzie will investigate day care centers within walking distance of the Crowder's house and will talk over the options with Theresa.
2. Theresa will make a choice from the options.
3. If the publically funded day care centers are not available or are inappropriate for Mary, Lucy will arrange for Theresa to get financial assistance from the Department of Social Services or the hospital to pay the fees.
4. Lizzie and Theresa will enroll Mary together, as soon as possible.
5. Yvonne will try to get a friend to loan Theresa a stroller. If this doesn't work out, Lucy will ask social services to buy a stroller so that Mary can go to daycare.
6. Theresa will take Mary every morning to the center when she is well enough to take her. Julie will pick Mary up in the afternoons.
7. Lizzie will arrange for a home health aide or visiting nurse to help out during the day with Mary when either Mary or Theresa is not well enough to manage alone.
8. When Theresa and Mary are both well, Theresa will take Mary in her stroller to the park down the street once a week.

Criteria/Timelines:

The timelines are as listed above in the activities. Theresa will decide if she is satisfied with the way things are going and if her need has been met as specified in the outcome.

Child's Name: Mary Crowder

Outcome: # 3

Theresa and Julie want some help with mealtimes in order for Mary to learn how to eat more foods, be less fussy, and grow stronger.

Strategies/Activities:

1. Lizzie will arrange for a home nutritionist or visitng nurse to come to the Crowder's five evenings a week, beginning in two weeks.

2. The home visitor will help Theresa and Julie make a list of several finger foods that are good for Mary and that she likes and is able to eat.

3. The home visitor will show Julie how to make several easy to prepare dishes that Mary likes and is able to eat.

4. Anna Martinez, the WIN occupational therapist and Lizzie will do a feeding evaluation of Mary next week, before the home visitor comes to determine if Mary has any special feeding problems and will develop a plan with Theresa, which would become a part of this IFSP, to remediate the problem if one exists. The evaluation will be done at home at a regular mealtime.

5. Yvonne will continue to do the grocery shopping for the Crowder's, now using a list that Julie has made for her.

Criteria/Timelines:

The timelines are as listed above in the activities. Theresa will decide if she is satisfied with the way things are going and if her need has been met as specified in the outcome.

Child's Name: Mary Crowder

Outcome: # 4

Mary will have physical therapy in order to increase her body strength and mobility and make it possible for Theresa and Julie to take care of her at home.

Strategies/Activities:

1. Virginia Taylor, the hospital physical therapist will visit Theresa and Mary at home once a week to monitor Mary's motor development for signs of loss of previously attained skills.
2. Virginia will work with Mary on her balance and righting reactions. She will show Julie and Theresa how to play with Mary in a way that gives her practice in these activities.
3. When Julie plays with Mary, she will play in the way that Virginia is teaching her.
4. Lizzie will come to one of Virginia's sessions every month to learn how Mary is doing.

Criteria/Timelines:

Mary's therapy will begin next week. Virginia will use clinical observation to judge Mary's progress or Mary's maintenance of previous motor skills, and will do a formal evaluation jointly with Lizzie every three months to monitor Mary's motor development

Child's Name: Mary Crowder

Notes on the IFSP Process:

Lucy Crawford, Theresa's hospital social worker, referred Theresa and Mary to Project WIN. The WIN assessment staff planned a transdisciplinary arena assessment with Theresa, Yvonne, and Julia. Lucy became part of the team for the assessment.

Following the assessment, Theresa decided to enroll in Project WIN with Mary. Lucy is part of Theresa's IFSP team, along with the occupational and physical therapists from the project. Yvonne and Julie are on the team, and Lizzie O'Leary will work with Theresa as her service coordinator.

Because Theresa and Mary have ARC, they may need the services of many agencies other than the hospital and Project WIN. New members will be added to this transagency IFSP team by Theresa, or with Theresa's consent as the need arises.

Theresa was very clear about the kinds of support she needed and plans to tell Lizzie any time she needs or wants a change in the IFSP for Mary, Julie, Roger, or herself. Because Yvonne may need to take over for Theresa at any time should she become too ill to care for her family, Theresa has asked that Yvonne be a full member of the team and have access to all the records relating to Mary and the Crowder's IFSP.

Back Cover Sheet – IFSP

Project WIN
77B Warren Street
Brighton, MA 02135
(617) 783-7300

Child's Name: Mary Crowder

Birthdate: 12/10/86

Address: 1715 NE Adams St. #527

Boston MA

Phone: 362-4347

Service Coordinator (Case Manager): Lizzie O'Leary, R.N.

IFSP Team Members and Signatures:

Theresa Crowder, mother Theresa Crowder
Yvonne Baker, Aunt
Lucy Crawford, M.S.W.
Virginia Taylor, L.P.T.
Anna Martinez, O.T.R.
Lizzie O'Leary, R.N. L O'Leary

Frequency, Intensity, and Duration of Services:
Services will begin immediately and continue until Mary is three years old and eligible for public school preschool. Frequency and intensity will vary; See individual outcomes

IFSP Review Dates: 12/15/88 6/15/89

3/15/89 9/15/89

Transition Plan: x **Not Applicable** _____ **Yes, (see outcomes)**

Parent Signature(s):

This plan represents our wishes. I (we) understand and agree with it, and I (we) authorize Project KAI to carry out this plan with me (us).

Theresa Crowder — 9/15/88
Parent(s) **Date**

APPENDIX E

DEVELOPMENTAL ASSESSMENT RESULTS FOR A SAMPLE OF 10 WIN CASES: RESULTS FROM ADMINISTRATION OF THE HELP DEVELOPMENTAL ASSESSMENT INSTRUMENT (FURUNO, ET. AL., 1979)

Birth date Age Test 2	Developmental Age Test 1 Developmental Age Test 2 (+ = maintaining dev. age equivalence) (- = below dev. age equivalence)

Case #	COG	LANG	FM	GM	SOC	SH	Comb.
DOB: 7/25/86 CA 1: 14 mos CA 2: 23 mos	16+ 29+	16+ 26+	13- 25+	14+ 25+	14+ 30+	13- 31+	14+ 28+
DOB: 9/22/87 CA 1: 4 mos CA 2: not tested	4+	4+	5+	5+	6+	6+	5+
DOB: 9/25/85 CA 1: 3 mos CA 2: 17 mos	4+ 20+	4+ 22+	4+ 18+	4+ 21+	5+ 24+	5+ 19+	4+ 21+
DOB: 8/27/86 CA 1: 7 mos CA 2: 20 mos	8+ 25+	9+ 25+	8+ 24+	7+ 25+	7+ 26+	7+ 23+	8+ 25+
DOB: 2/21/87 CA 1: 14 mos CA 2: 21 mos	15+ 23+	14+ 24+	17+ 23+	21+ 26+	17+ 24+	17+ 22+	17+ 24+
DOB: 3/6/87 CA 1: 15 mos CA 2: 20 mos	15+ 21+	14- 22+	17+ 23+	21+ 26+	18+ 22+	18+ 22+	17+ 23+
DOB: 11/29/86 CA 1: 11 mos CA 2: 26 mos	16+ 21-	12+ 25-	10- 24-	11+ 25-	9- 25-	9- 25-	11+ 25-
DOB: 3/7/87 CA 1: 9 mos CA 2: 13 mos	6- 7-	5- 6-	5- 6-	4- 6-	6- 8-	6- 6-	5- 7-
DOB: 1/25/87 CA 1: 3 mos CA 2: 9 mos	4+ 8-	3+ 8-	3+ 8-	3+ 8-	4+ 9+	4+ 9+	4+ 8-
DOB: 2/26/87 CA 1: 12 mos CA 2: not tested	12+	12+	10-	12+	13+	13+	12+

KEY:

COG = Cognitive Domain
LANG = Language Domain
FM = Fine Motor Domain
GM = Gross Motor Domain
SOC = Social Domain
SH = Self Help Domain
DOB = Date of Birth
CA = Chronological Age
CA1 = Chronological Age at Test 1
COMB = Combined Developmental Age Across All Domains

APPENDIX F

Goal Attainment Scale for Family ID# Sample Project #WIN Interventionist#_____ Date:____

Attainment Goal 1 P=2 Goal 2 P=1 Goal 3 P=2 Goal 4 P=3 Goal 5 P=2
levels

	HOUSING	ASSERTION	DAY CARE	ADDICTION	EMPLOYMENT
+2 Best Expected Success With Intervention	Moves into own place	Always asserts parenting skills in nondefensive manner	Child accepted into amenable day care and enrolled A	Attends daily NA meetings and contacts sponsor daily A	Mom begins part time work
+1 More than Expected Success With Intervention	Lives in 2 bedroom apt. with non-user A	Often asserts parenting skills A	Mom completes appointments and visits sites-does not follow through	Begins attending NA meetings	Calls and considers several employment options A
0 Expected Level of Success With Intervention	Successfully adapts to current situation	Sometimes asserts parenting skills	Fills out applications and calls sites	Chooses specific NA meeting time and place	Completes interview process for MBTA
-1 Less Than Expected Success With Intervention	Partially adapts to current situation	Rarely asserts parenting skills I	Discusses steps for day care application with case manager I	Discusses NA positively with case manager	Completes applications for job at MBTA
-2 Most Unfavorable Intervention Outcome	Stays in same situation I	Never asserts parenting skills (backs down when E. disgrees)	Mom takes no positive steps toward day care	Refuses to discuss NA I	Takes no active steps toward employment I

P= Priority I= Initial Performance A= Attain Level

WIN SAMPLE GOAL ATTAINMENT SCALE